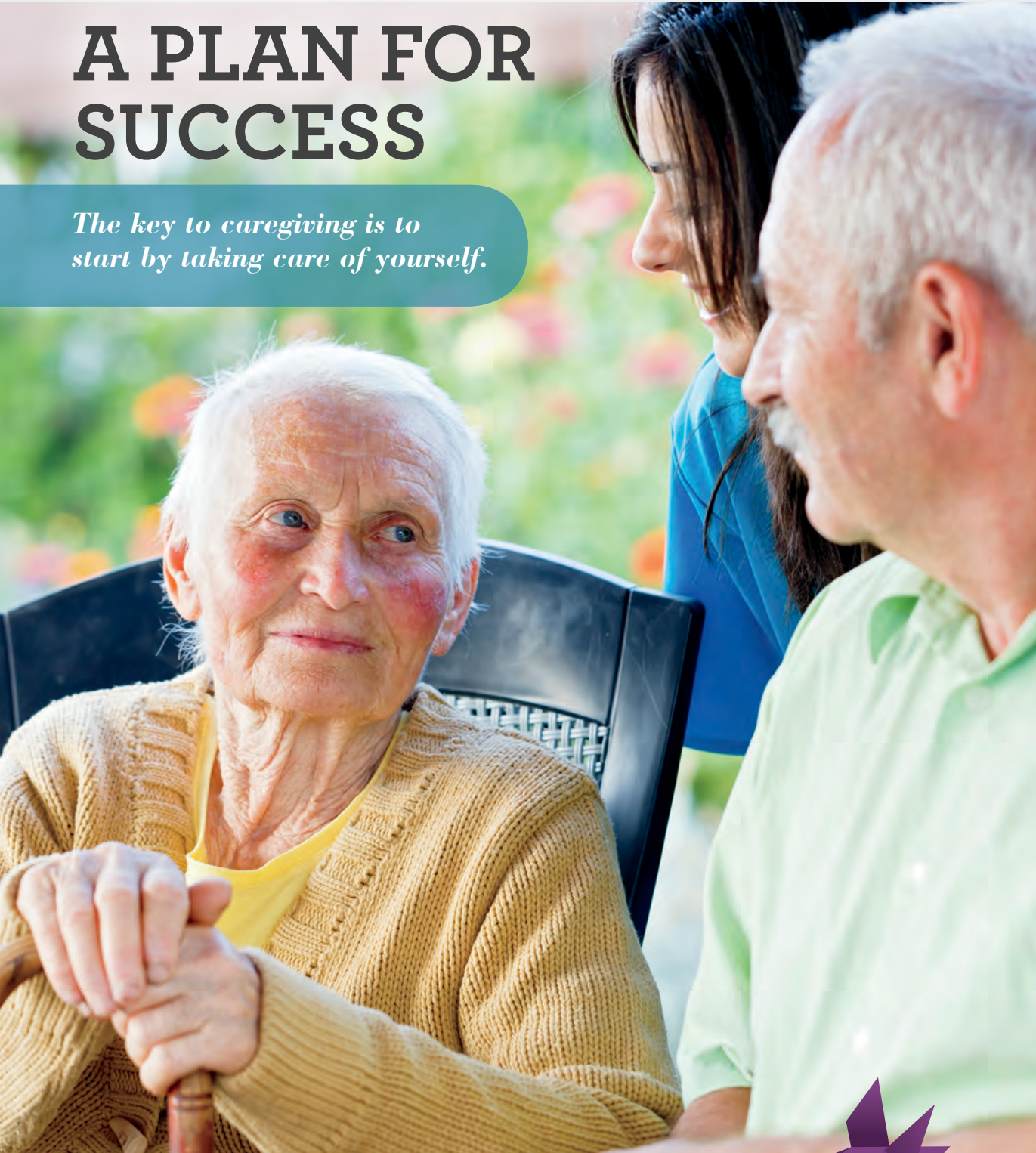


# CAREGIVING...

## A PLAN FOR SUCCESS

*The key to caregiving is to  
start by taking care of yourself.*



**HOSPICE**  
**B U F F A L O**

*Care for them. Comfort for you.*

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## FAMILY TESTIMONIAL

*“Everyone we dealt with on the Hospice Team including the volunteers were professional, compassionate and very giving.”*

*~ Lori, North Collins*



*Creative and Printing Services Generously Donated by Chakra Communications, Inc.  
Researched, Developed and Written by Sara Montz, LCSWR, ACSW*

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## INTRODUCTION

**Caregiving offers you and your family a unique and meaningful time with your loved one.**

It can be a time for closeness and reflection. It can also be a stressful time. Because of the demands of caregiving, it is important to take care of yourself; self-care will enhance your caregiving skills and the quality of time you have with your loved one.

When beginning the experience of caring for a loved one, we seem to have unlimited energy. We rise to the occasion with untapped adrenaline. After a while, however, we begin to wear down, previous energy doesn't seem to be present. This is a signal that we need to attend to our own needs if we are going to be an effective caregiver.

Caring for your own needs will offer great benefit not only to you but to those in your care. This booklet will assist you in finding balance and organization through a period of time that may be very new to you. Being a caregiver often brings new roles and responsibilities that may be unfamiliar and feel overwhelming. By identifying both your needs and the needs of your loved one, this booklet will help you identify positive steps and coping strategies for managing some of the stresses involved in caregiving.

# CAREGIVER QUESTIONNAIRE

Please take a few minutes to complete the following questionnaire so that we may identify your needs as a caregiver. Please discuss your concerns with your hospice social worker at the next visit.

*As a caregiver, I would like more help/information about:*

	YES	NO
Medical procedures I provide ex. providing safe movement, wound care etc.	<input type="checkbox"/>	<input type="checkbox"/>
Giving medications	<input type="checkbox"/>	<input type="checkbox"/>
What to do at the time of death	<input type="checkbox"/>	<input type="checkbox"/>
Changes to expect at time of death	<input type="checkbox"/>	<input type="checkbox"/>
How to communicate with health professionals	<input type="checkbox"/>	<input type="checkbox"/>
How to communicate with my loved one	<input type="checkbox"/>	<input type="checkbox"/>
Spending quality time with my loved one	<input type="checkbox"/>	<input type="checkbox"/>
Developing skills to take care of myself	<input type="checkbox"/>	<input type="checkbox"/>
Balancing time between my loved one and the rest of my family	<input type="checkbox"/>	<input type="checkbox"/>
Legal and financial issues	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual concerns	<input type="checkbox"/>	<input type="checkbox"/>
Finding appropriate resources	<input type="checkbox"/>	<input type="checkbox"/>
Feeling closure with my loved one	<input type="checkbox"/>	<input type="checkbox"/>

## GETTING ORGANIZED

Trying to manage all of your caregiving responsibilities will be easier if you have an action plan. You may find it helpful to share your plan with those around you.

### Step 1:

Make a list of all of your loved one's needs. A list including personal care needs, medical appointment needs, daily activity needs, and home care needs is a place to start. A blank chart for your use is on the following page.

### Step 2:

Determine which needs you can manage on your own. Be careful not to take on more than you can handle.

### Step 3:

Determine who can assist you with some of your loved one's needs. Consider family members and friends. If some family members work, maybe they could take care of paying the bills. Accept offers from friends to assist you. Most friends really want to do something for you. They want to feel a part of the caregiving. You may want to ask friends to run errands or to borrow a favorite book on tape from the local library. It can be very helpful to have friends provide rides to doctors appointments. Some patients enjoy being read to or appreciate the preparation of a favorite food item.

### Step 4:

Make a master list for the month as to who will be responsible for which activity, on what day and time. Patients also find this helpful because it keeps them apprised as to who will be visiting or assisting them on a particular day. This master list is also very helpful to your health care team. Keep the list in view maybe even on the refrigerator.

## FROM THE 79 YEAR-OLD WIFE OF A TERMINAL PROSTATE CANCER PATIENT:

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*“It ’s hard. It ’s very hard. In the beginning I wanted to do it all, but I find I can’t. You have to decide what to prioritize. You have to decide what is important at the moment. If the dishes are in the sink, it ’s ok. There’s always laundry; it is ok if you don’t fold it right away.*

*Prioritize: first the patient then everything else.”*

# PATIENT CARE/NEEDS

Check all that apply and provide name of responsible caregiver.

## Medical Care

Daily administration of medication

\_\_\_\_\_

At home medical procedures (dressing changes etc.)

\_\_\_\_\_

Communicating with health care team

\_\_\_\_\_

## Personal Care

Feeding

\_\_\_\_\_

Bathing

\_\_\_\_\_

Toileting

\_\_\_\_\_

Dressing

\_\_\_\_\_

Ambulation/Exercising (movement of patient)

\_\_\_\_\_

Other

\_\_\_\_\_

## Household Care

Cooking

\_\_\_\_\_

Cleaning

\_\_\_\_\_

Laundry

\_\_\_\_\_

Shopping

\_\_\_\_\_

Other

\_\_\_\_\_

## Medically Related Errands

Drugstore

\_\_\_\_\_

Transportation to Medical Appointments

\_\_\_\_\_

Supportive Care/Supervision

\_\_\_\_\_

Friendly Visiting

\_\_\_\_\_

Checking on patient

\_\_\_\_\_

Supplementary Home Health Aide Assistance

\_\_\_\_\_

Volunteer Assistance

\_\_\_\_\_

Financial Issues Paying Bills

\_\_\_\_\_

Banking

\_\_\_\_\_

Insurance Issues

\_\_\_\_\_

Will/Estate Planning

\_\_\_\_\_

Name of Responsible Caregiver

## CAREGIVING: IT'S A FAMILY AFFAIR

Families experience many changes in their familiar routine when a loved one is faced with a life threatening illness. The family roles change to fit the needs of the caregiving situation. Until new roles are defined, families may feel as though they are in a state of turmoil. It's important to recognize that these feelings are normal and make the necessary adjustments.

This may be the first time that you have been a caregiver so you need to find a system of caregiving that works for both you and your loved one. When you don't have a manageable routine, caregiver strain becomes apparent. This can manifest itself in different ways. You may find that you don't have the patience you once had. Sometimes caregivers distance themselves from the rest of the family and in turn become angry that no one else is providing care. Are you feeling fatigued because you haven't asked for help because you believe you can do it better? Emotional stress can also strain relationships.

Good communication is essential and will make your caregiving experience a positive one. Your hospice social worker is available to assist with your concerns and can arrange a family meeting to address these issues if needed. You will feel more in control if you take action to take care of yourself and ask for the help you need. Review the dialogue on page 9 and consider how you might use these suggestions to promote better communication.





## CAREGIVING: IT'S A FAMILY AFFAIR



### TIP FROM A CAREGIVER

*“Sit down and write down everything. Get prepared; find out everything you can — resources, where you can get help and things like that because they really need that up front because when they hit that wall, It’s really helpful to know the options. It helps to have it all in writing.”*

### ASKING FOR HELP FROM FAMILY/FRIENDS:

Discuss problems before they become overwhelming. It is important to ask for help before you become resentful of your role as a caregiver. “I feel so alone sometimes. I need help managing the care.” Asking for help either from family or friends can be very difficult. Most of us have been taught from an early age that we need to be independent and self sufficient. We may think that asking for help is a last resort. Beginning a sentence with “I” can be a sure way of not putting someone on the defensive. It lets the person know how you feel and what your needs are.

#### Practice:

“I need help with Mom on Friday morning. I was hoping you could take her to her doctor’s appointment.”

#### Practice:

“I will be attending a meeting on Wednesday. Can you stay with Dad for a few hours?”

It is not helpful to start a sentence with “you” because you will place the other person on the defensive as indicated by the following example.

#### Example:

“You always have an excuse when I ask for help with Dad.”

Friends often want to help but don’t know what is most helpful to you or your loved one. When you are completing the Patient Care Needs Chart on page 7, ask a friend to make a trip to the library or grocery store. Friends generally want to be involved if they offer to help. Take them up on their offer! It gives them a chance to give back and feel a part of the care plan. Caregiving can be an unexpected “gift ” for personal growth.

## DIFFICULT DISCUSSIONS

### Difficult Discussions with your Loved One

Most of us struggle when faced with having a difficult conversation with the loved one in our care. We have no rehearsal or script for these conversations. We may be afraid of upsetting our loved one and worry that they may not be in the same place that we are. Because of the uncertainty of the time we have left, it is probably better to have these conversations sooner than later. To postpone your planned discussion may mean you have missed the opportunity. Your loved one may also be having the same concerns. He/she would like to talk about fears, hopes and end-of-life concerns but may be afraid of upsetting you. Talking about end-of-life issues has historically been discouraged. Sometimes those closest to us will distance themselves. If talking is difficult, try writing your loved one a note or card. Your hospice social worker is available to assist you with these difficult conversations.

**Consider some sample conversations below:**

### Consider Rephrasing:

**Mom, You're going to feel better...**

**I wanted you to complete a Health Care Proxy.**

**I'm always tired. No one does anything to help around here...**

**Don't be depressed.**

**Everything will be alright.**

**Mom, This must be difficult for you...**

**Let's talk about how you'd like our health decisions managed?  
Is that O.K.?**

**Maybe we should think about getting some more help....**

**I am here for you...**

**Let's talk...**

## POINTS OF DISCUSSION

Trying to manage all of your caregiving responsibilities will be easier if you have an action plan. You may find it helpful to share your plan with those around you.

### 1. Questions for the Team

While you are caregiving for your loved one, you may have questions that you forgot to ask during your team member's visit. If these questions are urgent, you should not hesitate to call your Hospice team. If you want to ask them at the next visit, write the questions down so you don't forget. It's easy to forget with so much on your mind.

### 2. Talking to your Doctor & Hospice Team

Be rested and organized. Remember you are the advocate or champion for your loved one and it's o.k. to have expectations of your physician. Use language that portrays confidence.

"I need...", " My mother needs...", " We need..."

Assist your loved one in developing a list of questions and concerns. Prior to a physician or hospice nurse's visit, it is important to make a list of your questions and concerns. Your hospice nurse can assist you with a list for the physician. Prioritize your list. Start with the most important items, in the event time is limited. Whether you are at home for the doctor's visit or at the doctor's office, it is important that someone be with the patient. This is very helpful in recalling what was discussed. It can be overwhelming for the patient to try and remember everything and we all hear things differently.

### 3. Spiritual Care

Our belief system can affect our caregiving. If we believe in a loving Creator who holds out mercy, eternal life and a future reunion, we may find strength in that belief. If we trust that our loved one will continue to finish that which is unfinished, to reach a level of perfection in another life, we may assist them with our strength and allow them to complete their own destiny. If we are uncertain about what comes next, or if we do not believe in an after life, it may be important for us to surround our loved ones with love and appreciation as they complete their journey here. Oftentimes, family and friends identify feelings of powerlessness as their loved one nears the end of life. As caregivers, we do not control what comes next, but we can surround our loved one with support and love while they are with us. Avoid making promises you are not able to keep. Patients may ask caregivers to promise that they will die at home or never go to the hospital again. It is unwise to make promises that are beyond our control. With our inability to see into the future, we can only respond in the most supportive manner in each situation.

The Nurse, Social Worker, and Chaplain are able to provide support for you and your loved one during this important time in life.

## POINTS OF DISCUSSION

### 4. Relaxation Techniques

Meditation allows us to focus on one thing that is pleasant for a period of time. It helps us participate in conscious relaxation in order to put aside stress and anxiety in hopes of achieving calm and peacefulness. This may be a time for you to practice meditation and self care.

Muscle Relaxation is another technique that assists our body's response to stress. Relaxing our body can also lead to a relaxation response emotionally. Your caregiver role will be enhanced if you take care of yourself.

### TIP FROM A CAREGIVER

*“Go to God first; ask Him to lead you and guide you and give you peace. Find the positives in it — within all the difficulties there are. There are also great feelings that you can get of gratification, satisfaction so on and so forth; it ’s a warm thing and if you open your doors to the positive that is actually given, it will make you stronger rather than burdened.”*

- Written by Hospice Buffalo Chaplain,  
Robert Fink, M.Div.

## MAKING A PLAN FOR SELF CARE

Caregiving is one of the most rewarding yet difficult jobs you will ever have. Caring for a loved one can trigger many emotions.

Emotions can range from anxiety about how you will manage your caregiving role, to concern about how your family will manage in your loved one's absence, or concern about your loved one's future needs. Feelings of sadness, crying, sleeping too much or too little, a lack of interest in family and friends, changes in appetite, or difficulty concentrating can be signs of depression. Do not hesitate to discuss these feelings with someone close to you and/or with your hospice social worker. You may find yourself losing patience with those close to you because you're angry at the situation you are in. You may have feelings of helplessness to change what is happening and losing patience over the smallest things.

Guilt can come from feeling that you aren't doing enough for your loved one or those around you (even though you are). You may be feeling that you shouldn't do anything pleasurable, or feeling guilty because you may be healthy. You may have grief, which is often referred to as anticipatory grief, because you're feeling the impending loss, the loss of closeness with others because time for others is less, or grief about your changing role at work and home due to caregiving responsibilities.

If any of these feelings become overwhelming, it is important to ask for help from your family and /or a professional. Your Hospice social worker is available to address your concerns. A list of resources is also available in the back of this booklet.

*“What you need to do is take it day by day, even if you find yourself doing it moment by moment because if you get a good moment with a person, you gotta enjoy it because you know the next moment might not be so good. And you do learn that you were worried about the dumbest things; when something like this happens you realize what 's really important.”*

## MAKING A PLAN FOR SELF CARE

**To cope with your emotions,  
a plan for self care is important.**

- 1 Set aside a designated time each day just for yourself...maybe early in the morning before anyone else is awake.
- 2 A regular routine of exercise is invaluable.
- 3 Talk about your feelings with a friend or family member. It helps lessen the intensity of these feelings when they are discussed.
- 4 Plan a regular dinner date with a friend so that you have something to which you can look forward.
- 5 Set priorities. Try letting housework go for a day.
- 6 Call a friend to stay with your loved one.  
Recheck your caregiver list.
- 7 Private hire a person to stay with your loved one.
- 8 Write down your thoughts/feelings in a journal.
- 9 Listen to your favorite music.
- 10 Learn relaxation techniques and/or listen to a relaxation tape.  
Ask your social worker how to explore this avenue.
- 11 Ask your social worker about a support group.
- 12 Keep a stress log to review with your social worker.

## CAREGIVER BILL OF RIGHTS

- 1 I will be compassionate with myself.
- 2 I will make time everyday for myself and will not feel guilty.
- 3 I will provide the best care possible for my loved one and will not judge my decisions.
- 4 I will accept the fact that no one is perfect.
- 5 I will realize I cannot do this alone.
- 6 I will ask for help from my family and friends before I feel overwhelmed.
- 7 I will give myself permission to cry if I need to.
- 8 I will not set aside my hopes and dreams even though they may be silent for awhile throughout this journey.
- 9 I will not lose contact with my support system.
- 10 I will not set humor aside and will welcome opportunities for it.

## The Serenity Prayer

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*God, grant me the serenity to  
accept the things I cannot change  
courage to change the things I can  
And the wisdom to know the difference...*  
*Dr. Reinhold Niebuhr 1932*

## CAREGIVER RESOURCES

### CAREGIVER RESOURCE CENTERS

#### **Erie County Caregiver Coalition**

95 Franklin Street - 13th Floor  
Buffalo, NY 14202-3968  
Ph: 716-858-8526  
[www2.erie.gov](http://www2.erie.gov)

#### **Family Caregiver Alliance**

758 Market Street, Suite 750  
San Francisco, CA 94103  
Ph: 1-800-445-8106  
[www.caregiver.org](http://www.caregiver.org)

#### **National Alliance for Caregiving**

4720 Montgomery Lane, Suite 205  
Bethesda, MD 20814-3425  
Ph: 301-718- 8444  
[www.caregiving.org](http://www.caregiving.org)

#### **National Family Caregivers Assn.**

10400 Connecticut Ave.,  
Suite 500  
Kensington, MD 20895  
Ph: 1-800-896-3650  
[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

#### **Other WEB Sites**

[www.caregiving.com](http://www.caregiving.com)  
[www.caregiver-information.com](http://www.caregiver-information.com)  
[www.caregivershome.com](http://www.caregivershome.com)

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### LOCAL CONSUMER HEALTH INFORMATION

#### **Aaron Health Sciences Library**

Buffalo General Medical Center  
100 High Street, D4  
Buffalo, New York, 14203  
Ph: 716-859-2827  
Fax: 716-859-1527

#### **Emily Foster Health Sciences Library**

The Women & Children's Hospital  
of Buffalo  
118 Hodge Street - 1st Floor  
Buffalo, New York 14222  
Ph: 716-878-1987  
Fax: 716-878-7547

#### **Medical & Science Library**

#### **Roswell Park Cancer Institute**

Elm & Carlton Streets  
Buffalo, New York 14263  
Roswell Park Community Cancer  
Resource Center  
Ph: 716-845-8659  
Fax: 716-845-3098

#### **Suburban Health Sciences Library**

Millard Fillmore Suburban Hospital  
1540 Maple Road - Ground Floor  
Amherst, New York 14221  
Ph: 716-568-6540  
Fax: 716-568-3030



# CAREGIVER RESOURCES

## FINANCIAL RESOURCES

### **Social Security**

Ph: 1-800-772-1213  
[www.ssa.gov](http://www.ssa.gov)

### **SSI: Supplemental Security Income**

(Based on Financial Need)  
Ph: 1-800-772-1213  
[www.ssa.gov](http://www.ssa.gov)

### **Medicare**

Ph: 1-800-(Medicare) 633-4227  
<http://medicare.gov>

### **Medicaid**

Ph: 1-855-355-5777  
or 716-858-6244  
[www2.erie.gov](http://www2.erie.gov)

### **Erie County Office of Veteran's Services**

Ph: 716-858-6363  
[www.erie.gov](http://www.erie.gov)

### **HEAP - Home Energy Assistance Program**

Ph: 716-858-7644  
[www.erie.gov](http://www.erie.gov)

### **Food Stamp Program**

Ph: 716-858-8347  
[www2.erie.gov](http://www2.erie.gov)

### **Verizon Life Line (Phone Discount)**

Ph: 1-800-837-4966 or  
1-888-641-8722  
[www.verizon.com/lifeline](http://www.verizon.com/lifeline)

### **EPIC**

### **Elderly Pharmaceutical Insurance Coverage**

Ph: 1-800-332-3742  
[www2.erie.gov](http://www2.erie.gov)

### **Central Referral**

(Lists community support agencies according to need)  
Ph: 211 or 1-888-696-9211  
[www.211wny.org](http://www.211wny.org)

## HOSPICE BUFFALO BEREAVEMENT SERVICES

Your Hospice social worker, nurse, doctor, aide and chaplain have helped care for you and your loved one since your loved one's admission into Hospice. After the death of your loved one, the care for you and your family members continues through our bereavement program.

### Hospice Adult Bereavement Services Include:

- **Individual counseling** – Our counselors will make home visits and provide individual support, assessment and guidance, as you try to understand and cope with your reactions to the death of your loved one.
- **Correspondence program** – This self-help educational program provides articles and reading material on a wide range of topics relating to grief. It includes information on the phases, feelings and complexities of grief, with practical suggestions on how to deal with them.
- **Bereavement support groups** – These groups are run by professional staff, and allow grieving people the opportunity to be with others who have experienced a similar loss. Support groups encourage adjustment and healing.
- **Facility/Staff Support** – Bereavement counselors are available to support professional staff or to counsel nursing home roommates who have suffered a loss.
- **Educational Programs** – Programs are offered on grief related topics.
- **Times of Remembrance** – This event provides an opportunity to join the hospice staff and volunteers in remembering your loved ones.

### Hospice Children's Counseling Services Include:

- **Pre-death counseling services** – When a patient is admitted to hospice, the family becomes eligible for support for children through age 18. Counselors may visit the home to help children and their caregivers identify and express feelings and thoughts relating to the changes that are occurring because of the patient's illness.
- **Bereavement services for children** – Counselors from Hospice Bereavement use a variety of age appropriate activities to help children progress through their grief.
- **Support for caregivers** – Information and reassurance is available to caregivers of children. Our Hospice children's services are unique to the Hospice Buffalo Program.

Your social worker may have explained that someone will contact you to offer our services after the death of your loved one. In the next few weeks, you will receive a letter detailing our Bereavement Program. The letter will be followed by a phone call from one of our bereavement counselors. Should you have any questions or need anything prior to receiving a call from us, please feel free to call Hospice Bereavement Services at (716) 601-3888. We look forward to talking with you.



## FOR YOUR CONSIDERATION

### *A legacy of love.*

The Center for Hospice & Palliative Care provides services to patients and families regardless of their ability to pay and therefore we are in need of community support. Contributions in the form of memorials may be requested at the time of death and would assist us in providing these important services to patients and their loved ones. If you wish to designate memorial donations to the Hospice Foundation, please inform your funeral director.

Memorial donations may be made to the Hospice Foundation of WNY, PO Box 590, Buffalo, NY 14240-0590. The Hospice Foundation can be reached at 716-686-8090.

Thank you for your consideration.





*Serving individuals with serious illness and their families and caregivers, through a continuum of care spanning the course of illness and bereavement.*



**HOSPICE**  
**B U F F A L O**

*Care for them. Comfort for you.*

225 Como Park Boulevard  
Cheektowaga, NY 14227-1480  
Ph: 716-686-1900  
Fax: 716-686-8181  
HospiceBuffalo.com

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